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Jok M. Jok

WAR, SOCIAL TRANSITION, AND ILLNESS CONCEPTION: THE CASE OF TUBERCULOSIS IN SOUTH SUDAN

BEFORE THE Civil War resumed in South Sudan in 1983, efforts to combat tuberculosis were heading towards success. Today, however, tuberculosis is a serious health problem among the internally displaced and refugee population of South Sudan. (McCarthy et al., 1995). It is estimated that 20,000 Dinka live in displaced persons' camps and around relief centers in Northern Bahr el Ghazal of southwestern Sudan (hereafter Western Dinka). This region is inhabited by approximately 1.3 million Reik, Twic, and Malwal Dinka. The rest of the population is made up of Jur-Luo and Bantu-speaking groups who are scattered around the main town of Wau. Before the war, Wau functioned as the region's major commercial and service center.

Northern Bahr el Ghazal, due to its remoteness from international borders, its vicinity to the conflict zone between the northern government and the southern Sudan People's Liberation Army (SPLA), and many years of war-related destruction has become one of the most marginal areas of Sudan in terms of living standards, including poor levels of nutrition, hygiene, sanitation, and health care. The majority of the region's population subsists on cattle herding, small scale agriculture, trade, and fishing. All of these components of Dinka economy have been curtailed by government-sponsored Arab militia raids, resulting in severe food shortages and the displacement of the Dinka population. Among the displaced and war-impooverished communities subsistence strategies have shifted to wild food collection coupled with a dependence on meager and unreliable foreign relief delivered from northern Kenya under Operation Life-Line Sudan (OLS), a consortium of United Nations agencies and Non-governmental Organizations (NGOs).

While South Sudan has been the focus of numerous relief intervention programs, the area is still characterized by surmounting health problems and a

lack of many basic human needs. The dependence on outside assistance has not improved health conditions or food shortages of the larger displaced population. The outcome of war-induced impoverishment is a pattern of illness characterized by high rates of infectious and parasitic diseases. Death from respiratory complications, nutritional problems and many infectious diseases are a widespread phenomena. This disease pattern predominates in South Sudan's rural areas as well as in relief centers which have sprung up in the SPLA-controlled parts of the country, replacing and resembling the pre-war urban slums. Before the war, a combination of poor economy and the centralization of health services rendered rural health services nearly non-existent or very poor. Now, the destruction of service facilities due to war has increased the magnitude of the shortage.

The first effort to improve rural health conditions was initiated in the late 1970s by the World Health Organization (WHO) under its Primary Health Care (PHC) programs (House, 1989). PHC program goals included opening health posts as well as training community health workers (health educators and midwives) in basic medical techniques. By early 1980s rural health services were expanding and improving. The health units, which were generally known as dispensaries,¹ provided curative and some preventive services to the rural population. The main health units were headed by "Physician Assistants" and staffed by community health workers who were trained in the district hospitals of Gogrial and Aweil or at the regional hospital in Wau.

As in all contemporary societies, the introduction of primary health care programs to rural areas of South Sudan, in addition to the medical system inherited from the colonial administration and/or from Christian missionaries, made biomedicine more accessible to the Dinka. Both Western and traditional medicine are now used in a pluralistic fashion. The extend of the use of either practice depends on the local interpretation of illness according to ethnophysiological and religious beliefs, as well as accessibility of western medicine.

It has been suggested that changes in religious beliefs lead to the reconfiguration of perceptions about illness causation (Nichter, 1994; Westaway and Wolmarans, 1994 and Garro, 1990). However, the conversion of some Dinka to Christianity² has not been completely successful in changing people's notion of disease causation. Illness interpretation is still based on both biological causes and medical beliefs according to Dinka religious world-view. A disease may be caused by natural forces such as infections and parasites; but why a particular person gets afflicted is a matter decided by supernatural powers.

The result of this dual interpretation is that medical change in Western Dinka is a conflictive process. While people have tested efficacy of Western medicine, they have increasingly turned to it because it is believed to work, in

which case they maintain a distinct illness conception. But the region's varying degrees of exposure to urban culture and varying levels of accessibility of dispensaries give rise to different degrees of acceptance of Western medicine. In some cases, the use of traditional healing is a reticent reaffirmation of one's religious identity and deference for one's ancestors and other spirits who watch over the living.

The importance of this world-view for many pastoralist societies of South Sudan including the Western Dinka has made this a popular region for various anthropological studies. One of these (Lienhardt, 1961) is among the most important anthropological studies of the interface between religion, social organization, and economic items. The ethnographic literature on the area, however, does not cover health issues. A few works refer to health as a peripheral subject, in the context of traditional healing (Buxton, 1973) and over-all environmental and sanitary conditions (House, 1989). While these works relate economic conditions, medicine, social organization, and the changing cultural order, none of them focuses on particular public health problems; nor do they consider the health status of the population. This, of course, is no surprise given the history of anthropological enterprise. Its concern with specific public health problems in traditional societies was only incidental to a fascination with religion, magic, and general symbolism.

From November 1993 through February 1995 I conducted field research on the health conditions of war-torn South Sudan. Although my research focused on women's reproductive health, any researcher in South Sudan today runs the risk of ambitiously looking at every aspect of health, as very little research has been done in this area since the resumption of civil war in 1983. Therefore, tuberculosis (TB) being a public health problem of serious magnitude, I collected information on people's perceptions of its causes, and appropriate treatment as well as the attitudes of both patients and care-givers regarding contagion. My field-work was conducted in the relief center of Akon and adjacent villages. The village is inhabited by the Awan section of the Reik Dinka, and belongs to the district of Gogrial.³

Many cases of tuberculosis were diagnosed by relief health workers in Akon and a high incidence of the disease was expected in the entire region. For this reason, attention was drawn to studying patients and care-givers' perceptions of and treatment choices for this disease. Because this initially was not a subject of research interest, epidemiologic data are not exhaustive. This part of the study was mainly to gain ethnographic insights on the situation of tuberculosis and other respiratory complications control programs carried out by the French NGO, Médecins Sans Frontières (MSF), and United Nations Children Fund (UNICEF), in northern Bahr el Ghazal. These programs are not only for tuberculosis control, but rather for provision of basic medical care in

lieu of the non-existent state services. However, tuberculosis preoccupies many relief programs because of its apparent widespread. Yet, given the difficulties in control and treatment of tuberculosis in emergency situations, and because of the high rates of incidence, this disease represents one of the most difficult health problems that relief operations are grappling with.

This paper aims to generate an understanding of the influence of health beliefs on the Dinka's response to relief efforts for tuberculosis control. Due to extensive periods of contact with the biomedical system, people in Western Dinka often resort to buying biochemical treatments from local markets or smuggling antibiotics, primarily "streptomycin," out of the government-controlled town of Wau. They have also widely utilized the available relief services to treat tuberculosis and other respiratory problems perceived to resemble tuberculosis. Many of the patients diagnosed with tuberculosis were soldiers in SPLA. Their TB treatments were on and off due to their military duties or because their medical supplies periodically ran out. In-depth interviews with these patients provided detailed data on illness perceptions and the difficulties involved in making health care choices. During my stay in Akon several new patients were diagnosed; I closely observed them and helped to evacuate two, with serious conditions, to Kenya for prolonged treatment.

As I became aware of the difficulties involved in tuberculosis control, my interests in this disease became focused on the examination of the cultural conceptions of TB viewed within the contexts of absent medical services and the changing social order. I was trying to understand the role of these conceptions in patients' and care-givers' choice of treatment, once the person is thought to suffer from tuberculosis. Patients' attitudes toward the treatment regimen of tuberculosis became equally important. It was hypothesized in this study that strategies of dealing with a health care problem influence and are influenced by social beliefs and practices. Therefore, patients' attitudes toward tuberculosis are better analyzed in the socio-cultural contexts in which the illness occurs.

Methods

The data for this paper was generated through extended interviews with a total of 30 TB patients. Twenty-four were from Akon and the immediate vicinities. Two "self-diagnosed" patients were from Kuajok, south of Gogrial. Four patients who were diagnosed by MSF-Belgium were from the distant village of Lietnhom, east of Gogrial. These patients belonged to all walks of Dinka society. Twenty of the patients were men, and 10 were women. Ages are difficult to assess in an area where many people are malnourished and sickness is rampant, but it was speculated that most patients (21) were between the ages of 23 and 45.

This sample included 10 SPLA soldiers who nominally professed

Christianity, but also engaged in Dinka traditional religious practices. The rest were rural civilians who belonged to various indigenous Dinka religions. All the soldiers had at least completed elementary school, and 4 had also completed secondary education. The soldiers spoke Sudanese colloquial Arabic and had a fair knowledge of English. In Western Dinka, the ability to speak a language other than the native language of Dinka is associated with formal education or travel outside the region. Due to continuous political tension, the post-colonial educational policy in Sudan has caused the southern population to juggle between Arabic and English so that during the interviews with the soldier patients their responses were sprinkled with a few foreign phrases.⁴ But on the whole the interviews were conducted in Dinka and my language skills as a native speaker of Dinka were an advantage in this regard. Of course, the disadvantages of studying one's culture are many but none were significantly detrimental to the integrity of this part of my research project.

Many sets of questions were designed to elicit detailed data about the patients' ideas of disease causation, illness history, health-seeking behavior, diagnosis, and treatment first with traditional remedies, and then at the MSF-UNICEF relief clinic, or by buying antibiotics from the market or from individuals who may have obtained them from Wau. Questions were also asked on the duration of the treatment, efficacy, and perceived side effects of the drugs. The open ended nature of the questions allowed the patients to provide elaborate answers which were expanded to include any relevant illness experience or any other matters of concern to them. The subject of contagion never came up spontaneously and was usually asked at the end of the interview. I also asked questions on the possible role of evil eye and other unworldly powers in tuberculosis causation; people spoke normally about this. My overall project had initially started with eliciting household survey data including economic resources and their allocation, household composition and sleeping arrangements, eating habits and sharing of utensils, food distribution, and meal times.

Before seeking medical attention, patients had been self-diagnosed as suffering from tuberculosis (*hol*, *agolon*, *tueny pou*) and had had symptoms for more than a year. Most of them had sought various traditional treatments, used antibiotics bought from non-trained health providers, or had been intermittently using medically prescribed treatments. The symptoms described by patients included cough, chest pain, headache, and fever. When the patient is thought to have lost weight, or has difficulty in breathing, this suggested severity of the illness.

Due to the minimal health services available, patients in Western Dinka used all kinds of treatments they could find and had varying responses to treatment regimens. In order to examine how these decisions were made, I closely followed two Dinka men, one soldier and one civilian, who were

diagnosed with tuberculosis. The rest of the data was drawn from my interviews with the patients.

When I was resident in Akon in 1994, I accompanied the soldier patient, Lual, to the MSF-France clinic in Akon. Lual had been sick for over a year with much coughing, sometimes with blood, chest pain, and recurrent fever. He had been diagnosed with tuberculosis during his military service in the Equatoria region near the Zairian border, and was given short-course treatment. He was put on the six months regimen and was only given medication for the first half of the course to be supervised by his military unit's medical personnel. He was advised to return to the health center for the rest of the treatment after three months. Within the three months into his treatment, Lual's condition improved. At this time he was ordered to relocate to northern Bahr el Ghazal on military duty, and could not find an opportunity to continue with the remaining treatment. Now, whilst he was in Western Dinka, he became sick again and was told at the MSF-France clinic that his tuberculosis condition was severe. At this time, relief health services had ceased to provide treatment for tuberculosis because the disease was proving far beyond their capacity, and incomplete treatments were meaningless. Due to a combination of the complicated regimen of tuberculosis, and the fact that relief services were extremely limited, the relief agencies decided to refrain from attempting to treat and control tuberculosis. The only alternatives for Lual were either to return to Equatoria where services were better or to be evacuated to northern Kenya, where United Nations High Commissioner for Refugees (UNHCR), along with the help of some NGOs, had established a tuberculosis unit in the refugee camp of Kakuma. Both options were not viable for Lual: returning to Equatoria entailed a one month journey on foot, which he was already proving too weak to undertake; and evacuation had been discouraged by both the Kenyan government and the relief organizations. "If we cannot evacuate all those who need evacuation, why evacuate one?" inquired a frustrated relief worker.

The civilian patient, Macol, had a suspected case of tuberculosis for over a year and had consequently been taking streptomycin—generally recommended by family members or other knowledgeable individuals—which he obtained from various sources. Access to this medication was sporadic and Macol had an irregular usage of it. When I translated this medical history to MSF-France's doctor, she noted that this was one of the problems explaining why TB was so difficult to control. When there had been such intermittent treatment, a course of therapy would have to be extended beyond the standard course. If he were to be treated, according to the doctor, he would require a long-course treatment (up to 12 months).

In South Sudan, local medical personnel and relief health workers say that ideally, short-term treatment for TB should be administered by trained

persons only. If the patient has family members who have basic medical knowledge and who are willing to cooperate, they can occasionally help. But since the health care facility did not have consistent services, I offered to obtain the prescribed medication from Kenya for these two patients. After instructions I took responsibility in administering their treatment.

In September 1994, another soldier, Dhal, became sick again after he had received partial treatment, three years earlier, during his military training in Ethiopia. I also took his prescription, brought the medicine for him from Kenya, and supervised his treatment. Unfortunately, he could not complete his course of treatment because two months after he started the course, he had to return to his home village as he did not have a steady source of food. Three months later he returned with the hope of resuming his course of treatment. I helped him to be evacuated to the Kakuma TB facility in Kenya.

The rapport that I had developed with the patients and their care-givers benefited this portion of my project greatly. My involvement with them created an informal environment so that they were able to share with me various kinds of personal matters regarding the disease and beyond. For example, when Dhal was about to be taken to Kenya, he became extremely concerned about leaving his wife and child behind. They could not get the permission to board the UN plane with him. He was the only patient aware of the contagious nature of tuberculosis and was worried that he may have infected his wife. From this standpoint it was possible to closely observe the dynamics of patients' treatment perceptions.

Problems of Tuberculosis in South Sudan

Given the relative homogenous structure of rural South Sudanese societies in terms of economic resources, standard of living, and health conditions, the epidemiology of tuberculosis does not reflect any disparities among social groups and regions. In addition, given the inconsistency of health programs, lack of adequate medical tests, and the large number of new cases and high rates of death around relief centers, South Sudan ranks the highest among the various regions of Sudan in tuberculosis morbidity and mortality. Of all the nationally reported cases during the period before the war, South Sudan had an incidence rate of 42.0 per 100,000 population in 1982 versus a national rate of 16.0 per 100,000 population (UNICEF, 1982). Statistics for the period 1983-95 are non-existent. Considered together, the various relief agencies involved in health care⁵ in South Sudan sporadically reported approximately 250 cases in 1993 and 290 in 1994. Despite the dearth of reliable statistics, health care workers, both expatriate and local, speculated that tuberculosis occurred more frequently in South Sudan among the displaced populations inhabiting the areas with relief activity than among the still relatively stable communities.

In South Sudan, the only diagnostic means for tuberculosis used by the relief workers and local medical personnel is sputum culture. In their earlier efforts to treat tuberculosis, relief health programs recommended the use of a short-course regimen of six months duration. This treatment, which consists of an initial intensive phase of daily medication and a continuation phase of intermittent intake, requires strict supervision and administration by a trained health provider. Ideally, this would require patients to attend the health facilities regularly. However, the major problem with tuberculosis treatment in South Sudan is that health facilities, where they exist, are highly centralized in the relief centers. This would require the patients to move into the relief center for the duration of the treatment. This has proven impossible to do since patients have to either take family members along to look after them, in which case there is more food pressure; or go alone and, therefore, tend to themselves. The other major problem is that these relief centers are targets of military activity, creating many emergency evacuations of relief workers. Many treatment interruptions occur in this manner, and many patients never come back to the facility when relative security is restored. Therefore, long-course treatments were recommended instead.

During my stay in Western Dinka, tuberculosis had become such a serious health problem that people did not wait to have medical tests. People started taking medications (streptomycin, whenever they can find them) once they had symptoms perceived to be those of tuberculosis. When the local health units had the medications they dispensed them on the basis of a patient's symptom description, without medical diagnosis. Only the health facility of the relief programs closely followed general medical procedures concerning the detection of cases through transfer of specimens to Kenya, and the prescription of long-course treatment to patients, although they did not provide the medications. The assumption was that, if the patients were going to buy the medications nonetheless, they might as well be advised to buy the right course and receive the right instructions for use. The relief clinic emphasized to the public the necessity of clinical examination of patients and chest radiography. Only after this would they recommend the use of the standard regimen of 12 month's duration because the short-course treatment was destined to fail in such an unstable environment where patients are not closely supervised. The standard regimen included the use of streptomycin in the initial phase of treatment. But the success of this treatment depended on an uninterrupted supply of drugs and an improvement in the security situation. Both these conditions are not easy to come by, and prospects for tuberculosis control are grim.

Even if activities to control the disease were to be relatively successful from a medical perspective, various other factors still curtail the effectiveness of

tuberculosis treatment efforts in South Sudan. For example, due to some deep-seated conceptions about disease causation, it is still extremely difficult to identify cases at the early stages. This, therefore, defeats the purpose of efforts to control TB. During the PHC programs of the late 1970s, for instance, although attention was paid to tuberculosis and other respiratory problems, many people with no family history of the disease did not agree with the TB diagnosis and, therefore, refused to take the treatment. Today, the English acronym, TB, has become the popular term for the disease in South Sudan. It is a terribly stigmatized term that cannot be used around patients without causing offense. This still forces many people to discard the diagnosis of TB (Nichter, 1994).

More problems of control, as mentioned above, are due to the limited accessibility and the poor condition of health services (Westaway and Wolmarans, 1994). This relates to the fact that the distribution of the population in South Sudan is widely dispersed and centralized services are difficult to reach for the largely rural people. Travel to town was a difficult undertaking; doctors did not reach the rural areas, and PHC community health workers were not trained to manage serious health problems nor did they have the necessary facilities. Traditional beliefs about disease causation are also instrumental in the failure to control tuberculosis. Because of the belief that afflictions like TB do not occur randomly but rather in a premeditated order controlled by supernatural powers, indigenous remedies, including animal sacrifices to appease the gods, are largely practiced in combination with Western medicine before a trained health care provider is contacted. By the time a Western medical practitioner is consulted, the disease is often too far advanced, and may have developed complications from an inappropriate usage of medications.

Western Dinka: the Relevant Context

Economic and Social Organization

The village of Akon where I conducted fieldwork is located in the plains of northern Gogrial in the hinterland of Dinka Reik. It functions as the service center of the Awan section as well as the administrative capital of SPLA's local government. The Awan section of Dinka used to be inhabited by approximately 50,000 people. Now it seasonally hosts about 20,000 more displaced people who are attracted by the emergency relief services set up during a major famine in 1989. Cattle herding and small scale horticulture are the mainstay of Dinka economy. Supplemented with trade, fishing, and wild foods, this economy, under normal circumstances before the war, provided subsistence to the majority of Dinka population. However, thirteen years of civil conflict and the well-armed Arab militia raids throughout Western Dinka have caused massive displacement and loss of assets, thus there are clear-cut associations between the

political unrest and food shortages in Western Dinka. This warranted international emergency intervention in the form of humanitarian assistance. OLS established its southern sector to operate in areas under SPLA control. as opposed to the northern sector operating in towns controlled by the government of Sudan.

Partly as the result of emergency humanitarian assistance, a process of reconfiguration has occurred in the social organization in Western Dinka, particularly in Akon. The employment of younger people in the relief programs, although for meager food-for-work, repeats the tone of pre-war status differentials resulting from both the positive image of salaried jobs and from the reality of bias against rural people. While the war has brought destruction upon both rural and urban populations, and poverty abounds all over, there are still disparities in terms of access to resources. The sociopolitical organization of Dinka communities is now influenced by the militarization of the male population and also by the penetration of the culture of emergency assistance. Over the years, relief workers (both local and expatriate) have come to play a directive role in all community affairs. One can argue about the importance of community elders, the chief, and school teachers, but what cannot be denied is that the status of soldiers and of the people associated with the distribution of relief items is definitely higher for all practical reasons. These groups in Akon are clearly differentiated in terms of socioeconomic status. While most families in Akon depend on a combination of local resources (cattle and grain) and relief items, only people closely associated with relief efforts have been able to improve their economic conditions. Imbalanced improvement in economic status is reflected in the high-status individuals' ability to hire labor for their farms, sometimes using relief items to pay for this labor. Status differentials are also apparent in consumption patterns. Members of relief-workers' families have more clothing, blankets, and better cooking utensils.

As an agro-pastoralist society, the diet in Dinkaland is predominantly based on milk, sorghum, sesame, groundnuts, and millet. Meat consumption is occasional, for Dinka are extremely reluctant to slaughter livestock simply for meat consumption without an important occasion. The coming of an important guest, a marriage gathering, healing ceremonies, naming of age sets, a collective labor activity, and religious sacrifice are some of the events which necessitate the slaughtering of animals. Given the fluctuating environmental conditions, horticulture has increasingly fallen short of satisfying the nutritional requirements, and has created longer hunger gaps. During these gaps, slaughtering an animal for meat is necessary but still a shameful occurrence. Where there are strong kinship ties, this is not allowed to happen; well-to-do relatives provide a milk cow or grain to their poorer kin. Notwithstanding, food shortages over the last decade have caused flexibility in this regard. Decreasing cattle numbers,

due to raiding, sale, and disease, has reduced the dependability of children on milk. Ecologically, Dinka economy is best understood in terms of wet and dry seasons. Cattle movement, fishing, and trading according to these ecological conditions have always created seasonal hunger in this region. Now, forced movement has increased the gaps many-fold.

Health Conditions in Western Dinka

With war exacerbating the situation, what used to be a short lean period between the two seasons has now become almost year-round for many sectors of the population. Nutritional surveys carried out in Western Dinka in 1994 have demonstrated that rates of malnutrition are very high among children (MSF, 1994). Adults' poor diet has also reduced resistance to other diseases and has rendered many people susceptible to infections.

This poor nutritional status adds to the already insufficient sanitation to further aggravate the low health status in many communities in Western Dinka. Akon, centrally located and being host to all relief efforts, has become a home-base for many displaced and war-impoorished Dinka. These families remain as squatters who are given tacit permission by the host community to put up temporary make-shift huts along the river Kuom. Akon and adjoining villages, with an estimated population of 23,000 (displaced and permanent residents) in the summer of 1994, was not only the largest and the poorest of the relief centers, but was considered the center of civil administration with the population of the entire rural Northern Bahr el Ghazal looking up to it. With the administrative "capital" of the region being so poor, this is a sad indicator of the level of well-being of the region's population.

Over the last seven years many of the displaced and squatters of Akon have become semi-permanent residents and the make-shift huts have been replaced by homes of mud walls and grass roofs. The nearby food distribution center, the meager relief health services, and the individual friendships established with expatriate relief workers (including food-for-work employment) offer access to modern amenities such as kerosine lamps, batteries, cooking utensils, and food items like sugar, cooking oil, and wheat flour. However, the lack of sanitation and water supply remain life-threatening to the inhabitants of Akon, especially to children who are constantly exposed to parasitic and other infectious diseases. Garbage produced by expatriate UN relief workers is simply dumped outside the fences where dogs are free to scavenge and where many of the unaccompanied children of Akon forage and play.⁶ Pit latrines are only a privilege of the relief workers; the majority of households dispose of their human waste in the grass, which, when the rains come, is easily washed into the river that zigzags through the villages. In 1994, there was only one bore hole for clean drinking water. Toward the end of the year, Save the Children Fund-

UK constructed another bore hole. Yet, these were not enough for the 23,000 people. The queues to get the water were long, the tensions high, and tempers short as people competed for their turns. For many, the distance traveled from various villages to the bore hole was long. For these reasons, most people resorted to drinking from the river or shallow uncovered wells; infection rates thus soared, including that due to guinea worm.⁷

Cultural Change, Local Beliefs and Western Medicine

Many culturally patterned behaviors and beliefs including medical knowledge have changed so rapidly that very few people in Western Dinka have recollection as to when Western medicine was first introduced to the area. People would simply say that bio-medical practices were brought by the “Khwaja” (white foreigner) or the “Abun” (corrupted Arabic word for Abuna, meaning our father), the missionaries. While the colonial administration promoted the use of Western medicine in contempt for indigenous health beliefs, its widespread acceptance arrived only with the post-independence national government. In collaboration with UN agencies that popularized its use by introducing employment in community health programs, the national government adopted a flexible stance towards notions of superiority attributed to Western medicine, notions historically associated with the colonial regime. While the colonial and missionary health care was engaged in combat with indigenous popular health beliefs such as the evil eye, the role of ancestral spirits, and witchcraft both for being unchristian and for lacking naturalistic interpretations, the post-independence state/UN-supported health services were influenced by arguments for the role of cultural patterns in health. Therefore, since the end of the first round of civil war in South Sudan, especially during the hiatus between the wars (1972-83), state services in collaboration with international health agencies have acted as formidable agents of change creating the unpredictable hierarchy of treatment choices that rural South Sudanese make today. This also caused the genesis of the dual world-view regarding disease causation.

Today, although the interpretation of illness as a natural event or as a result of the action of supernatural beings is by and large divided between the rural, illiterate non-Christians, and the urban, literate Christians, this dichotomy is often blurry. While rural people still avouch that violation of social norms, evil eye, offensive acts against ancestors, and bewitchment are all possible causes of illness, other explanations largely imported from the Western medical system have taken hold among traditional Dinka. Yet, belief in naturalistic explanations of illness are not only a result of external influences nor of contact with urban elements, but are also a part of the traditional belief system which attributes certain illnesses to weather conditions (cold or heat), suppres-

sion of emotion (example, mourning, anger) and physical strength or weakness of the individual (resistance, immunity).

In traditional Western Dinka there is little consensus over the causes of illness that are in concordance with the Western medical point of view. While there is agreement that *acual*,⁸ dirt, can cause problems in one's health, there is little knowledge about germs and their role in specific diseases. There is general knowledge about the seriousness of minute organisms such as worms that one could drink with water, but there are no specific and systematic traditional preventative measures such as boiling drinking water.⁹

Despite the long history of contact with biomedicine, its scientific basis is out of the reach of the majority of people in Western Dinka, given that the level of education is very low. Even some of the patients in this study who had exposure to formal education and prolonged contact with biomedical ideas did not profess an understanding of the empirical basis of biomedicine, although they continuously included biomedical ideas in their illness interpretation. The result is a combination of different medical beliefs. For example, the most widely held ethnomedical belief is the application of traditional medicines directly to the area of pain. This, now also applies to *wal akim*, "doctor's medicine." The Dinka now have unabated preference for injectable medicines because they supposedly enter the blood system quicker and their efficacy and fast action is ensured.

This increased use of Western medicine and the assigning of secondary status to indigenous medicine has not necessarily forced out the traditional medicine. The use of the latter has even made an important presence under the current circumstances where state health care services have become obsolete. However, knowledge of traditional medicines is experiencing a decline as population movements and loss of assets have had two important consequences as far as traditional healing practices are concerned. First, under normal circumstance healers are usually consulted because they have established themselves over a long period of time. But under conditions of displacement where they may be far away from their community and residing where they are not well-known, fewer people use their services. Second, where "good" healers exist, they demand stringent compensations for their services. The result is that people will rather crowd a free health unit for biomedicine for whatever little service one can receive, rather than pay heavily for a traditional healer's services that have sparse prospects. Of course, the nature of a healer's specialty makes the difference. Those healers specializing in bone-setting, midwifery, and surgical procedures, for example, are more revered than those specialized in the areas of evil-eye aversion, appeasing bad spirits, or diagnosis based on direct communication with supernatural entities. The reasons for this selective trust came up in my conversations with some of the healers. In many instances they

appeared to be inconsistent about certain diseases they believed to be a result of the action of wizards, for example, and yet claimed that the biomedical hospital can also deal with them.

Nevertheless, biomedicine is not free from accusations and criticisms by the Dinka. But despite the local critique of biomedicine for its hierarchical structure, and for varying views over disease causation, biomedicine in Western Dinka has become the most widely trusted system. This is due to the long history of exposure by Catholic missionaries, the colonial administration, the state health service, and the present culmination by international health agencies. While the missionary and colonial health systems were against explanations of health and illness on the basis of magico-religious beliefs, the national state and international health services have little conflict with traditional beliefs and practices. Indeed, indigenous explanations are ideally viewed as a part of treating both disease and illness. Yet, the activities of internationally supported state health services have been more effective in tacitly combating Dinka traditional medical practices. Patients in Western Dinka believe that biomedicine treats the actual symptoms of a natural disease without attacking the traditional notions about why a particular person gets afflicted. In the words of some patients, "If the doctor at the health unit takes away my chest pain, the causes of this pain are irrelevant. . . ." "The explanation that the pain in my stomach is a result of a worm does not deny my belief that some supernatural entity, or some evil human being is responsible for the existence of that worm inside me . . . why not ask the doctor to kill the worm with medicine?"

Many factors are behind the changing medical beliefs: one primary factor was the introduction of community health workers by WHO's Primary Health Care programs. The increasing trust in Western medicine has raised the status of health workers and to be *Akim* is a most desired profession so much that to express affection for one's child or to praise her good nature, a person says that "this child of mine is going to be a doctor." At the present time, one Dinka medical doctor and a number of community health workers trained in the 1970s' PHC programs are practicing in their communities in Western Dinka through the support of relief health agencies. In 1994, there were 40 health centers in Western Dinka headed by these community health workers, coordinated by the MD, and receiving drug supplies from UNICEF. Some of these workers are very capable and experienced due to their previous training and to refresher courses run by UNICEF and health NGOs. The heads of health centers were often taken to Kenya to attend workshops on recent public health issues. These workers operate as a part of the local government relief organization, Sudan Relief and Rehabilitation Association (SRRA), and are compensated with food by relief agencies. They also have clandestine private practices. The medical doctor, based in Akon, sees a large number of people in the clinic

(approximately 100 each day), but accepts after hours consultations. He may demand payment for serious cases like those involving surgery.

This background indicates that the entire population of Western Dinka uses or desires to use Western medicine to a large extent. Even when other treatments are being tried, it is usually due either to the combination of the two medical systems, or to attempts to avoid undertaking a journey to the health center. Herbal medicine is also used for home remedies, but due to the flourishing business in patent medicines, the former is almost giving way at the market places.

So what factors influence the choice of either traditional or naturalistic medical strategies? Despite the high status accorded Western medicine and its apparent influence on health care choices of the people in Western Dinka, their decisions about when and from whom to seek care are influenced by their varying illness understandings. The choice of treatment is made according to the level of seriousness of illness. For example, *bec*, minor ailment, is handled at home, whereas *tuany*, serious sickness, is taken to *Pan Akim*, hospital. This choice is not always in the same order, however. Patients and their care givers continuously evaluate the condition and they go back and forth between the systems, not only trying different health workers but also switching and combining medications. Other factors in health care choice include the economic considerations. State and relief health care services are free and are most utilized when available, as opposed to obtaining medicines from the market or consulting a traditional healer who demands payment. The other major factor is the distance from the health unit. If the patient has to be placed under surveillance at the health unit, this requires important logistical arrangements that are difficult for most people in Western Dinka where travel is all on foot.

Tuberculosis in Western Dinka

Since relief services started operating on and off in Western Dinka in 1989, health NGOs, the International Committee of the Red Cross (ICRC), and UNICEF have reported numerous cases of tuberculosis in the region. When cases were frequently appearing in their clinics, they made attempts to initiate a control program. In 1989, ICRC, which was mainly concerned with the war wounded, was also re-equipping health units and providing basic medicines. During their visits to many health units in Northern Bahr el Ghazal, they frequently collected sputum samples from patients and took them to their base hospital in the relief transit town of Lokichokio, on the northwestern corner of Kenyan border. Of the suspected cases, a significant number tested positive. During brief interviews with ICRC staff in Lokichokio, it was learned that the organization was considering initiating TB treatments. However, given

the medical history that the patients provided, many of them were treated for some of the symptoms, but a full program could not be undertaken given the difficulties of supervising the patients, and apparent misuse of medications by the patients. Many more patients were also using medications just on the basis of symptoms suspected to be those of tuberculosis, especially recurrent cough, and not as a result of proper diagnosis.

When I arrived in Akon, MSF-France had been presented with a similar dilemma as the ICRC. During my stay in Akon in 1994, the three cases described earlier were part of a large number of patients diagnosed with active tuberculosis. All the patients with positive smears were supposed to be put on treatment programs utilizing the relief clinic under the supervision of MSF-France if the lead organization (UNICEF) had agreed to provide medications.

Shortly after health NGOs started to consider initiating the treatment program, all the difficulties involved became enormous that a decision needed to be made about who was to run a TB control program between MSF-France, UNICEF Resident Project Officer, who was an MD, and the Dinka MD. Apparently, none of the expatriate health workers wanted to commit to this task. The Dinka MD was willing but had neither facilities nor medications. This fear, on the part of expatriates, of "starting a program that could not be seen through," prevented the willing Dinka doctor from initiating and committing to the supervision of a program. Due to a lack of medical and logistical resources, he was unable to regularly visit the other health centers in the region. As a consequence, the community health workers heading their units had to manage their programs, including attempts to treat tuberculosis without proper diagnosis, and without supervision of the coordinating MD. If UNICEF had committed to supporting the program, the Dinka doctor would have had the means to enforce some guidelines about diagnosis and treatment. In this case, he would have discouraged the community health workers from recommending the use of TB treatment to all patients just on description of symptoms. In emergency situations like in South Sudan, chronic diseases do not appear to be the most pressing in the face of all the other health needs. For example, a child immunization program, guinea worm, malaria, diarrheal diseases, and reproductive complications all took the priority of relief programs.

Poverty, population movements, congestion in relief centers, overcrowding in sleeping spaces, low nutritional status, and poor health conditions, including infections, are characteristic of Western Dinka at the present time; this makes the region a suitable environment for tuberculosis. Particularly significant in transmission is the arrangement of social space. Dinka homesteads are traditionally made up of several circular huts. Each is normally shared by several family members. Under normal circumstances, the density is low. Thus this disease was previously very uncommon in rural South Sudan, but given the above conditions, massive exposure to tubercle bacilli is likely to be common

within the family, because more and more individuals are crammed into the huts. Transmission also occurs in the community as people crowd at the clinic, the food distribution center, and around the water bore hole. In addition, bovine tuberculosis is not well controlled at present, and of course the Dinka neither boil nor pasteurize their milk, the single most frequent item of diet (Fison, 1996). The soldier patients diagnosed during their military service had lived under extreme conditions of underfeeding and having to share a narrow sleeping space with many other guerrilla soldiers. Most of the civilian patients came from areas that had witnessed massive destruction and resultant severe impoverishment, and were compelled to settle near the crowded relief airstrips.

The scanty statistics obtained from health relief organizations show that most TB patients throughout South Sudan were between the ages of 21 and 40, the age range with higher rates of morbidity. Rates of infection were higher among young adult males. But almost all the female patients in Western Dinka were between the ages of 35 and 45, an age range consistent with the national pattern of morbidity and mortality. This pattern resembles the demographics of tuberculosis following massive rural urban migration during the years of famine in western Sudan (1984-85) and the displacement of a large southern population to the north (1986-88). During this influx, the majority of people were women and children, and their conditions were so appalling that tuberculosis infection rates among women reached unprecedented levels in the history of the disease in that country. This relates tuberculosis to poverty more closely than to family history. Of all the 21 patients in this study, only two reported a history of tuberculosis in their families.

The Dinka Explanatory Model of Tuberculosis

The Dinka language has many terms for tuberculosis. The most commonly used are *jong hol*, which literally means the disease of coughing, and *tueny pou*, meaning disease of the heart. *Agolon* refers to the tuberculosis that runs in families. The English acronym TB is also widely used, but *agolon* and TB have so much become stigmatized names that they are not used around the patients. Although the first two, normally-used terms refer to the same phenomenon as the stigmatized ones, the former are understood to refer to normal *hol* (cough), which projects a notion that this disease responds to treatment. Given the high mortality rate among TB patients, many people in Western Dinka assume that tuberculosis (*agolon* or *TB*) cannot be cured since it is the type that runs in families, and whose victims are not known to survive; whereas *tueny pou* or *jong hol* (cough) could be cured by Western medicine. However, the fact that patients afflicted by *agolon* and those by *jong hol* are both at the same level of risk of death if not treated, has brought two conceptions in Western Dinka. First, either the tuberculosis that runs in families actually runs in more families than previously believed. Or second, what used to be a normal

cough has become a fatal disease because of all the problems caused by war.

This conception takes a specific line between two categories of Dinka. (See Table 1.) Those exposed to urban, literate, or Christian culture through formal education; and the more “traditional” Dinka (the rural, non-literate, non-Christian). Upon adoption of urban culture, patients usually rejected the causal role of evil eye and the power of deities in illness. Most of these people attribute illness to biological or natural events instead (cold weather, alcohol consumption, etc.). The only traditional belief in supernatural powers about which the educated Dinka have not formed a universal stand against is the belief in the power of *bany bith*, the master of the fishing spear. This is the part of Dinka ideology that does not have serious conflicts with Christianity. Respect for the powers of *bany bith* is as true as the reverence for the words of a Christian clergy. The *bany bith*, when calling for punishment, supposedly does not specify the kind of affliction on the culprit, but upon his prayers, God can answer by causing any illness including tuberculosis. So it is in the domain of evil eye, sorcery, and other magical performances that a Dinka individual decides whether to remain traditional in illness beliefs, or to cease to be so and attribute illness to natural causes.

Table 1: Cultural-Explanatory Models of Sickness

	Beliefs Held by Rural Population	Beliefs Held by Urban Population
Ascribed Names & Types of Tuberculosis	curable: • jong hol (disease of coughing) • tueny pou (disease of heart)	
	incurable: • agolong or TB (runs in families)	
Ascribed Cause of Illness	tueny baai: • sorcery (evil eye) • deities • inappropriate past behaviors	tueny geo: • biological or natural
Why Illness Exacerbated in Recent Years	• curable types rendered incurable by civil war conditions • incurable types within families more numerous than previously thought	
Proposed Cure	• requires consulting a doctor or healer	• can only be treated by medical doctor

5. War, Social Transition, & Illness Conception

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The causal role of evil eye in tuberculosis in Western Dinka is often rejected by educated Dinka not only on the basis of their new culture, but also as a result of individual experiences with the disease. One patient with secondary school education enumerated many diagnoses that had been made by traditional healers about the genesis of his sickness. On one such occasion, the diviner had attributed the sickness to the angry spirit of an unmarried dead brother of the patient. Another healer suggested that the patient's difficulty at breathing was a result of the blood of people the patient had killed in war. The patient discarded all of these explanations, because he suspects that his condition began before the death of his brother and before he joined the war.

When the patients were asked about the doctor's explanation regarding the role of mycobacteria in their illness, many of them recalled those explanations, but could not make the connection in medical terms. Only one patient I interviewed had worries about infecting his family members, and therefore, wondered if someone else infected him. The majority of patients and caregivers, both literate and traditional, explained the illness in terms of exacerbation of cough, and poor diet. The role of the evil eye was held high exclusively by traditional Dinka. Fifteen patients mentioned the existence of *agolon* in their families' distant past. They could not recall any specific person in their family for the previous five generations who had had the disease, but they remembered that their clans suffer from the stigma of being known to have the disease.¹⁰ The second largest causal category is poor diet, which is also explained as weakness, lack of resistance, or weight loss. This category, along with other lower rank causes, falls in the rubric of causes generated by war. (See Table 2.) These

Table 2: Causal Explanation of Tuberculosis Given by 97 Patients

Explanation	N
Exacerbation of a cough	27
Poor diet (weight loss)	19
Evil eye	16
Runs in family	15
Cold weather	12
Use of artilleries	5
Alcohol consumption	2
Contagion	1

include the use of mortars in combat,¹¹ sleeping in the open during displacement or travel in the forest at night (which exposes people to cold weather). Poverty and excessive work were constantly mentioned by care-givers and other non-patients.¹²

My interviews revealed that most patients only learned from the health workers about tuberculosis in terms of minute organisms that cause infection. The level of comprehension of this knowledge provided by the health centers varied, however. The idea that tubercle bacilli were spread through the air from an infected person to other people was difficult to conceive. Upon realization that people in Western Dinka are not aware of the danger of contagion, that patients are surrounded by family members, and sleeping space and eating utensils are shared, the relief health services started telling people about the necessity of changing these arrangements. Most Dinka expressed the impossibility of such prejudiced attitudes against one's sick relatives (Pocock et al, 1996).

The cultural conceptions of tuberculosis held in Akon indicated that biomedical explanations of this disease still do not make sense to the Dinka. Although educated and some traditional Dinka acknowledge the biological basis of tuberculosis, the connection between tuberculosis symptoms and microorganisms remain ambiguous to them. Indeed, the biomedical explanation of tuberculosis have been incorporated into Dinka interpretations of illness in general. For example, traditional healers are now often found using medical conceptions like "breathing microbes into the air," borrowed from the health centers to explain illness. These pluralistic diagnostic theories make it difficult for the Dinka to fully accept a biomedical approach. Although it is important for them to interpret illness on the basis of their cultural repertoire, the life-threatening nature of tuberculosis, the potential of social interaction to spread it, and the best way biomedicine could contribute, were not a part of the shared community knowledge. This was exacerbated by the widespread nature of other respiratory infections, and this allowed many people to ignore their cough as an early symptom of tuberculosis, therefore, hindering early diagnosis. The diagnosis of many advanced cases strongly attest to the difficulty in detecting the disease early on.

Patients' Perceptions of Treatment

Tuberculosis is a chronic infectious disease that requires extended therapy, which must be completed. Irregular or incomplete treatment can compromise the cure, cause drug resistance, and give rise to relapses (Sumartojo, 1993 and Toman, 1979). But it is often observed that TB patients, as with patients of other chronic conditions, experience many difficulties in following a prolonged drug regimen. Patients discontinue medications for various

reasons. Access to care, cultural conceptions of therapy, and improvement in their conditions are some of the most commonly noted reasons behind patients' dropout from therapy.

In Western Dinka, irregular therapy was considered a major contributor to the escalation in TB infection rates. It was mainly a consequence of the lack of a consistent control program. This pushed patients and their care-givers to obtain medications on their own without proper instructions and supervision of experienced health care workers. This privately sought treatment is obtained according to the availability of medications in the market, and according to the financial situation of the patient. Since the market was stocked on a smuggling basis, medicines were not necessarily existent at all times. Advice provided by relief health workers to encourage the patients to seek skilled persons' supervision has raised the level of awareness about the problems of intermittent treatments. However, the question of the distance from the health centers, the difficulty of obtaining the right amount of medication, and the predicament of sufficient follow-up remain unabated.

Observations of patients that I had close contact with indicate that delayed diagnosis, the use of market medications before proper diagnosis, and irregularities of treatment due to military service or because of the logistical obstacles of moving closer to the health unit, many patients' full cure would be impeded by insufficient follow-up even if the treatments were available. Tuberculosis treatment involves many changes in the patient's life-style, and so I felt that the two patients with whom I had close contact should be helped to show that even if the treatment is free, success of TB treatments requires adherence to the regimen, close supervision, and resources of the patient if she has to move (Durrheim and Belt, 1996). When the two patients were taken to the UNHCR TB facility in Kenya, their conditions improved greatly by the time I left the field in 1995. Their understanding concerning the importance of the long course and availability of UN feeding services were instrumental to their commitment to the treatment.

Discussion

Public health and emergency relief efforts to control chronic illness are hampered by various factors, foremost, the shortage of service, access to care, and organizational problems of service delivery. These factors are in the domain of physicians and other health professionals, and are usually beyond the patients' control. Yet, cultural influences and individual aspects of illness experience in attempts to treat patients with tuberculosis represent important obstacles in formulating successful control programs. Patients' compliance with medical regimens and adherence to doctor's recommendation are vital components of an effective tuberculosis control program (Sumartojo, 1993). As the

ethnographic data presented here shows, problems of tuberculosis control involve both local medical beliefs which can obstruct biomedically based interventions. This requires intervention programs to seek a better understanding of the common grounds between medical systems. This common ground could be used as basis for health education.

As this study shows, effective patients' response to the complicated regimen of tuberculosis treatment and to the advice of health personnel can only be obtained upon a strong rapport between the patients and health care providers (Dick and Schoeman, 1996). One of the primary strategies for effective tuberculosis treatment and for increasing patients' adherence to it, is the provision of short-term supervised therapy (Wilkinson et al, 1997). This ensures constant provision of information and support that patients need in order to stick to the treatment. Because tuberculosis treatments were not medically condoned in Western Dinka, there was no long-term contact necessary for the stimulation of positive responses between the patients and health care workers. The importance of supportive contact in adhering to the regimen for a long period of time was evident among patients who had closer contact with health relief workers. Those who did not maintain contacts almost invariably behaved contrary to the advice of health care workers.

Difficulties in tuberculosis control in Western Dinka, however, cannot be blamed on patients' attitudes toward treatment. They are largely due to the inexistence of health programs devoted to tuberculosis. The condition of health service facilities, the problems of cross-border relief operations, security interruptions, and the importance accorded to other more immediate health problems, are all problems that prevent expatriate health workers from initiating tuberculosis therapy programs. Relief health agencies argued that if these relief workers cannot closely supervise the program and provide adequate instructions to community health workers as to patient follow-up, such a program is destined to fail. Even if the local level constraints were to be overcome through mass education, insistence upon setting up such a program will still suffer from macro-level pressures, particularly funding of relief agencies to recruit more personnel. It would be extremely difficult to sell a long-term health program under an emergency situation to donor agencies. As mentioned earlier, emergency situations present relief agencies with more pressing health needs, and chronic illnesses often take secondary position on the list of needs.

Conclusion

This article has addressed the reemergence of tuberculosis as a serious public health problem in a Dinka community of southwestern Sudan. Changes in social organization due to war, displacement, and loss of assets were central to the rise of tuberculosis. This article was concerned with patients' reactions

to the disease. In Western Dinka pluralistic understandings of tuberculosis, lack of medical services, and the inconsistent availability of patent medicines in the market led patients to seek treatments on their own. All the therapies sought in this way did not conform to the medical regimen; they were incomplete and interrupted by both logistics and insecurity. Both cultural conceptions and individual patient perceptions of disease causation were shown to have impeded full acceptance of biomedical explanations. Other factors relating to patients' conditions also led to interrupted therapies. While the relief health services attempted to raise awareness about the causes and proper treatments, they could not offer much in the face of other more immediate emergencies.

Many studies of tuberculosis and other chronic illnesses have emphasized the fact that sociocultural factors and individuals' lived experiences are as important as health care organizational factors in disease control (Barnhoorn and Adriaanse, 1992, Sumartojo, 1993, Westaway and Wolmarans, 1994, Nichter, 1994). With this acknowledgment, we can draw some general conclusions from the ethnographic data of illness conception and treatment choices in Western Dinka. As shown in the history of health services in South Sudan, problems at the policy level influence the operation of local level services, and this in turn affects individual health seeking behavior. While health behaviors may be modeled according to shared cultural knowledge, lived experiences of individual patients are also central to health care choices. Therefore, a program to control tuberculosis in a society that is undergoing a rapid sociocultural transformation will require addressing health care structural factors (health education, screening, supervised therapy) in conjunction with sociocultural considerations (illness conceptions, values, patients' conditions).

Notes

- ¹ These facilities were run by community health workers, some of whom were trained in basic hygiene. The dispensary only provided basic medications such as malaria treatments, and clearing and dressing tropical ulcers. They occasionally dispensed antibiotics such as penicillin and streptomycin. The ailments for which some of these medications were prescribed were not clinically tested.
- ² Christianity in Western Dinka has only taken hold among urban dwellers and makes up of about 15 percent of the region's population.
- ³ Before the war, Gogrial was the second largest commercial and service center closer to this research area after Wau. From the colonial times up until 1995, when SPLA civilian administration was set up, Gogrial was known as district. Now, although under the control of the government of Sudan, it is a country.
- ⁴ This has created an interesting linguistic problem. It is rare for bilingual or trilingual Dinka to hold a steady conversation in Dinka without using a few English or Arabic words.
- ⁵ The NGOs providing health relief included, in addition to MSF-France, MSF-Belgium, UNICEF, Medecins Du Mond, CCM, Sudan Medical Care, Norwegian Peoples' Aid, CARE, Oxfam, and save the Children Fund-UK.
- ⁶ Due to breakup in many families, there is large number of children whose parents have either been killed, starved during the 1989 famine, or have migrated to the north. These children may have a relative who looks after them, but resources are so scarce that children end up being marginalized.
- ⁷ A terribly debilitating disease, it has reduced the work force so much that it is one of the leading factors in accounting for the unsuccessful harvest that Western Dinka has witnessed over the last five years. Gogrial district has the highest rates of guinea worm infection in the world.
- ⁸ There are clear efforts to reduce *acual* from contaminating the food. Anybody preparing food, milk cows, breast-feeding, or handling household utensils, must was before hand.
- ⁹ Despite the knowledge of water-borne diseases, many Dinka people had no conception of Guinea Worm contraction being water-related. Indeed, they expressed wonderment at educational relief efforts to promote water filtering.
- ¹⁰ Two patients with suspected family history of the disease mentioned that their clan's daughters have been rejected in marriage for fear of carrying the disease with them to other families.
- ¹¹ Use of heavy artilleries in combat is thought to shake the chest. Soldier patients expressed certainty that it forms at least a part of the origin of their sickness.
- ¹² This category of cause is not considered one of the root causes of tuberculosis but definitely exacerbates the patient's condition. This was not mentioned by any patient, and I asked about it. The response varied, but most related to modesty about one's labor contribution. Most patients expressed their worries that they were not contributing much to the household, and so to complain about "too much work" was to be ungrateful for the care provided by their families.

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